



Info Sheet 1: An overview of Coronavirus (Covid-19) and rare disease

What is the coronavirus (Covid-19)?

Coronaviruses are a family of viruses that typically cause disease in animals but can 'jump' to humans. The first human coronaviruses were identified in the 1960's as a cause for the common cold. The coronavirus that is now causing infections in lots of people first started in China at the end of 2019, and it is believed it was transferred to humans from bats.

Covid-19 has spread to nearly every country in the world. It has been difficult to control partly because it behaves differently in different people. Some people will just have a mild infection that does not require admission to hospital. Around 1 out of every 5 people will have a severe infection and need to go to hospital. It has been estimated that out of every 100 people who get infected, between 1 and 3 people will die. Older people seem to be at the highest risk of having a severe infection. At the same time it is thought that many people who have the infection may have no symptoms at all, and this makes it harder to control.

The coronavirus is very contagious through coughing, sneezing and touching surfaces previously touched by an infected person. People can be affected very differently by the virus, but for many people it can cause a fever and dry cough. For some people it can cause severe breathing problems.

Children may be affected differently by the virus, for example they may have very non-specific symptoms such as sore throat, runny nose, vomiting or diarrhoea. Children may not have a fever or a cough, and some may have no symptoms at all.

I have a rare disease and I am worried about Covid19 - what should I do?

It is important that you talk to your GP or healthcare provider about your concerns. If you have carers you should talk to them as well. If you are a member of a patient support group it is worthwhile checking in with their website, as they may have information about COVID19 available.

If your healthcare provider agrees that you fall into the 'extremely vulnerable' category then you will need to 'shield' i.e. isolate yourself and not go out for 12 weeks. You can read more about the different risk categories and what to do in **Info Sheets 2, 3 and 4**.

To find out what you can do if you develop symptoms see **Info sheet 5**.

If you have carers it is important that you have an alternative plan in case your carers get unwell. Do you have medication and enough food? Can you get these delivered to your house? Make a list of friends and family who might be able to help out. For advice regarding carers coming to your home see **Info Sheet 6**.

I have a rare genetic condition but I haven't received a letter to say I am at high risk. Does that mean I don't have to worry?

Not necessarily.

It is very tricky to identify all the people who are at high risk of Covid19. Unfortunately, some people who are at higher risk have not received a letter and some people who are probably not at increased risk have received a letter to say that they are at high risk. If you are unsure, we

recommend that you look at **info sheet 2** to work out whether you are at higher risk. If you think this may be the case, talk to your GP, hospital doctor or nurse who can give you more advice.

What should I do to protect myself from Covid19?

There is still a lot we do not know about the coronavirus and we are learning new things every day. For now, there is no treatment or vaccine available. It is important that we are all very careful with hygiene as prevention is the best strategy. You can read more in the following sections:

Info Sheet 2. What makes a person more vulnerable to Covid19?

Info Sheet 3: Understanding your risk from Covid19 if you have a rare disease

Info sheet 4: What should I do if I am an extremely vulnerable person?

Info Sheet 5: What to do if you have symptoms that could be due to Covid19?

Info Sheet 6: Advice about carers entering your home

We are also producing a more detailed extra information sheet which includes details of important risk factors for some of the more common rare diseases. This document (***Additional information on specific rare diseases and risk from Covid19***) also lists additional sources of support and information for specific disease groups and will be available very soon.

These information sheets were written and produced by Dr Elizabeth Forsythe, Dr Lara Menzies, Kelly Kohut, Dr Nicki Taverner, Professor Eamonn Sheridan and Dr Frances Elmslie, on behalf of the British Society for Genetic Medicine, the Clinical Genetics Society and the Association for Genetic Nurses and Counsellors. We would also like to thank Emily Clarke from Genetic Disorders UK for invaluable input and also Beth Coad and Ginny Attard for their help with Info Sheet 6.

Version 1.1 created 9th April 2020

